

Harnessing social media networks to share information about stem cell research and treatments

Original publication:

Leveraging Social Media in the Stem Cell Sector: Exploring Twitter's Potential as a Vehicle for Public Information Campaigns

Author:

Kathleen McNutt, Amy Zarzeczny

Demand has driven the continued growth of unproven stem cell treatments offered in private clinics around the world, despite regulations and restrictions on stem cell use in many countries. Social media offers a tremendous opportunity to use social networks as a way to inform the public about stem cell research and the risks involved with unproven treatments. Recently, a public information campaign using Twitter was designed to explore the potential use of online networks as a way to share evidence-based information and encourage people to engage in discussion about stem cell-related topics.



What questions & challenges are raised?

There is evidence showing that the Internet and social media are being used to market unapproved stem cell treatments directly to patients and families. The safety of these treatments is often questionable. In some cases, they may cause more harm than good, and may have little to no benefits despite their sometimes large financial costs. Yet, growing demand has spurred the numbers of clinics offering unproven treatments to climb, even in the US and other countries with stringent regulations. In situations like this, organisations and governments often try to provide information to influence people's attitudes and behaviours. These efforts, called public information campaigns (PICs), are increasingly conducted online using social media, but there is currently limited research on their effectiveness, particularly for PICs focused on stem cell treatments. In their recent paper, Dr Kathleen McNutt and Professor Amy Zarzeczny at the University of Regina used Twitter to explore the use of online networks as a way to spread information about stem cell research and the risks of unproven treatments, and to encourage people to engage in discussions about this topic. Their study provides insight into some of the opportunities as well as the challenges of using social media for PICs.

potential, but in order to maximize their impact, more research and studies are needed to better understand social media behaviour, how to measure engagement and how to assess the impact PICs have on people's knowledge of a subject matter and subsequent behaviour.

What insight & direction does this give for research policies?

This exploratory study highlights several potential opportunities, limitations and challenges of social media-based PICs. Although influential users showed limited participation, the authors' data demonstrate how social media can amplify information distribution. Forty-eight initial tweets resulted in 258 active responses by other users, over a five-fold increase. The authors note that most users responded to the PIC by retweeting to their own networks, a moderate level of engagement. This retweeting expanded the potential reach of the PIC. The authors point out that, unfortunately, there is no way to know exactly how many individuals viewed the PIC tweets and that any activity in response to the PIC without the hashtag couldn't be tracked. A major challenge the authors discuss is that future PICs will need to learn how to more effectively get influential users to participate in sharing the information in the first place. The authors also note that this work, as is often true of traditional PICs, does not tell us whether the information provided has any impact on people's behaviour. Dr McNutt and Professor Zarzeczny close their paper by pointing out that online PICs have

What background and point are discussed?

Dr McNutt and Professor Zarzeczny's research highlights several advantages of using social media as a platform for PICs, including potentially large audiences and the opportunity for people to engage with each other and to add content. Notably, social media has the ability to promote information to users from sources they trust, which is particularly important in the context of unproven and unapproved therapies, because research suggests some individuals interested in pursuing these treatments do not trust doctors or established medical research organisations. The authors chose Twitter as their social media platform because it has been shown to play a role in social learning and to potentially influence health behaviours. Its structure also lends itself to having influential users (individuals or organizations) with large networks of followers, which is useful for broadly distributing information. The authors used an approach referred to as "network governance" and identified 100 influential Twitter users and invited them to participate in their stem cell treatment-focused PIC. The influential users were asked to send tweets over a two-month period referencing a patient booklet titled "What you need to know about stem cell therapies" (written by Professor Timothy Caulfield and Dr. Zubin Master) along with a hashtag for monitoring user activity. The results of this exploratory study show that three out of the 100 influential users contacted actively participated, sending 42 tweets over the two months of the PIC. Six other users also sent out a single tweet. The initial tweets from the participating organisations alone had the potential to reach a total of 12,129 Twitter users, as measured by their numbers of followers on Twitter. Importantly, social media allows viewers to engage with information and discussions at different levels, such as passive viewing, promoting posts, and allowing users to be 'co-creators' by adding their own comments and content. The authors determined that their PIC stimulated 169 users to retweet posted messages and 89 users to mark that they liked different tweets. In addition, the authors documented eleven users who engaged with the PIC at a higher level by adding their own content to their tweets about the campaign.